INTERAGENCY COORDINATING COUNCIL STATEWIDE VIDEO CONFERENCING THURS, DEC 5, 2013 1pm to 5pm

Approved 1.17.14

PRESENT

Members:
Tina Bay
Scot Hoeper
Tammy Gallup-Millner
Jacki Harasym
Sen. Nicole Poolman
Jolyn Wasem
Carol Brakel

Wendy Borman Nancy Skorheim Holly Major Amanda Lausch Shawnda Ereth Jill Staudinger

Staff:

Colette Perkins Roxane Romanick

Guests:

Keith Vavrovsky – ND Life Skills and Transition Center Allison Skari – ND Life Skills and Transition Center Lindsay Heilman – Solutions Behavioral Healthcare Professionals

The meeting was held via conference call for the first hour and half due to the polycom IVN system not being able to support the meeting. At about 2:30, the polycom/IVN system was able to support visual and audio connections for the meeting. One Council member did try to attend the meeting at the Devils Lake site, but was unable to be connected by phone or polycom. The meeting adjourned at 5:00 p.m.

TOPIC: APPROVAL OF AGENDA

TOPIC: FAMILY STORY

• Kirsten Dvorak was present at the Bismarck site to provide her family story. Kirsten is the new regional consultant for Pathfinder Parent Center. She has outreach responsibilities for the Region VII area and also the state tribal organizations. Kirsten is a mom to a fourteen year old son who has a diagnosis on the Autism Spectrum. He was born on Nov. 25, 1999 after a normal pregnancy. They even went home after 24 hours due to lack of complications. Kirsten noted that he was extremely colicky. At 9 months, he stopped growing and gaining weight. This is when they started to run a number of health tests and got sent on to a nutritionist and other specialists. In the spring of 2001, they had CT scans and MRIs. A friend asked if it could be autism. They were referred to Early Intervention for

speech/delays. In April of 2002, they were airlifted to Washington, D.C. for additional testing. After a number of tests and developmental screenings, the health experts made a diagnosis of autism. They moved back to states and he was progressing. In 2003, they headed to Oklahoma City and qualified for Extended School Year. He has received special education services as well as outpatient therapy services. Today after all of the supports and services early on, he is a pretty typical eighth graders and wants an account on Facebook. Kirsten noted that she hopes that with her job at Pathfinders, she can use her knowledge to educate other parents.

TOPIC: MINUTES REVIEW 3/14/13, 6/6/13, 9/26-27/13

- A motion was made by Carol Brakel and seconded by Tina Bay to approve the March 14, 2013 minutes as distributed. Motion carried.
- A motion was made by Tina Bay and seconded by Carol Brakel to approve the June 6, 2013 minutes as distributed. Motion carried.
- A motion was made by Amanda Lausch and seconded by Holly Major to approve the September 26 and 27, 2013 minutes as distributed. The date at the top says "2027" this will be changed to 2013. Motion carried.

TOPIC: Members UPDATE:

- Carol Brakel reported that they are very busy in Region 1 and that Early Intervention referrals have been coming in rapidly.
- Scot Hoeper reported that foster care caseloads in Grand Forks County have risen by 70% and these involve a large number of young kids. The question was asked whether or not this is typical for the state in general and Scot stated that he didn't know.
- Holly Major noted that she currently has two of her own children on IEP's; her daughter with Down syndrome and her son. She noted that her daughter completed Early Intervention and is doing awesome.
- Amanda Lausch noted that she is now a parent of 4 kids as she and her husband have adopted two children from the Fargo area and they are special needs adoptions.
- JoLynn Wasem reported that she is mom to two girls and that the youngest is on an IEP due to speech and language concerns related her cleft lip and palate. They are currently dealing with changes of speech pathologists; both privately and in school, but otherwise things are going great.
- Keith Vavrovsky noted that he is glad to join. He is a social worker at the State Life Skills and Transition Center (formerly the State Developmental Center). They are currently serving nine youth at life skills and transition center. The youngest is twelve years old and two are nineteen. They continue to access services through the public school system.
- Lindsey Heilman noted that she is present as a guest to get information. She is with Solutions, Inc. They have a mental health mobile crisis unit in Fargo and are starting a rehab program in Fargo to serve adults and children; Their office in Fargo is by the Ground Round.

- Tina Bay reported that the traditional waiver for persons with Intellectual Disabilities/Developmental Disabilities contains the funding mechanism for Early Intervention services and is up for renewal. Currentl, individuals can submit public comment by Dec 31st on the renewal language. The Centers for Medicaid and Medicare has 90 days to review the renewal. Highlights in the renewal are pay points for Early Intervention services. Tina noted that there is built in growth for capacity every year. The waiver capacity grows by 105 slots every year and for the next 5 years. Reserve capacity in the waiver is for 19 of which 135 is for Early Intervention. The same criteria for reserve capacity is being submitted in this waiver.
- Shawnda Ereth noted that her triplets are now seven. Two have been diagnosed with cerebral palsy and are on IEP's. All three had Early Intervention services.
- Tammy Gallup-Millner noted that the program she works for and represents on the NDICC pays for diagnostic and treatment services for kids with special health care needs. Tammy noted that recently they were asked by the federal Maternal and Child Health Bureau completing a survey about what services are covered through their state Children's Special Health Services program. She thinks that perhaps they are trying to investigate whether or not there is a duplication of services due to the Affordable I Care Act. There continues to be concern about underinsured families as well as uninsured children and families. Staff working on testing of new Medicaid system. The CSHS Clinic directory will be coming out for 2014 and will be mailed in Jan. as well as placed on the CSHS website. Tammy noted that ND's Maternal and Child Health Division will be gearing up for the needs assessment that needs to be completed every 5 years for their MCH-B grant. Also the analysis of the national survey on children with special health care needs is completed and the link is http://www.ndhealth.gov/cshs/cshs.html. Tammy noted that Minot State University will be submitting a grant for continuation of newborn hearing screening. Tammy added that their department continues to explore the additional possibilities for newborn screening. Their department continues to deal with complex needs of families attempting to navigate the various health care systems and supports. This appears to have increased over the past year.
- Wendy Borman reported that last spring, the Department of Human Services Mental Health Department, applied for a federal system care of expansion planning grant and that this was awarded in July, 2013. The state has been organizing and conducting preplanning on how to implement Trauma-informed services is in our state. The state has been working with residential facilities to implement Trauma-informed services. Currently, the state has just finished administrative rules and given facilities some flexibility on implementation. A two day training on Trauma Informed care was held in Bismarck. The attendees left with project plans and in one year they can tell us what they have done the past year for trauma informed care. State office staff are staffing a lot of cases that are involving high need youth who are in a residential setting in our state and struggling to maintain that placement in our state.
- Senator Nicole Poolman, currently serves on the Senate Education committee. She is a parent of two children, one who is on the Autism spectrum.
- Jill Staudinger noted that she is an ICC member that serves in the provider role as she is the Infant Development director in Dickinson/Region VIII. They currently

serve around 150 kids now. They have seen CAPTA referrals increase and they are seeing a lot of babies who were premature. Their agency is also managing the Right Track program which is doing screenings for children and staying busy. It continues to be difficult to find staff in the area due to the oil boom economy.

- Roxane reported on the following:
 - The Pathfinders Parent Involvement conference is April 10, 11, and 12, 2014.
 - Jennifer Barry, Early Childhood Administrator for Department of Human Services, asked that the information regarding the Inclusion Support Program for children with special needs in child care setting be announced. \$700000 was allocated in the last legislative session. \$300,000 was allocated for a contract that was issued to Child Care Aware for them to hire two Inclusion Specialists who will be located on the west and east sides of the state. Missi Baranko, a former Early Interventionist was hired for the western half of the state. The inclusion specialists will be providing technical assistance on specific cases in child care settings. \$400,000 was allocated for granting through the Department of Human Services. The grant requirements are currently on the website at this link: http://www.nd.gov/dhs/info/pubs/docs/cfs/inclusion-support-grant.pdf. The granting requests will be taken on an ongoing basis vs. at designated times in the year. The grants can be used to increase staff to enhance supervision in child care settings, as well equipment, supplies, and environmental modifications.
 - Moe Schroeder, Family Voices of ND, asked to report that Family Voices will be conducting focus groups around 3 Bright Futures topics – child development, youth and sexuality, mental health and children. The focus group on Child Development will be held on December14th in Williston.
 - Attended meeting with Prevent Child Abuse ND (PCAND) who received the latest federal Early Childhood Comprehensive Systems (ECCS) grant. PCAND also has the federal home visiting grant. The ECCS grant has been designated to enhance developmental screenings options in ND, primarily for birth to 3 year olds. The current focus is on assuring that mental health screenings are completed. The meeting Roxane attended was for stakeholders to give input about possible activities. A representative from the American Academy of Pediatrics also attended. Materials relating to the stakeholder meeting indicated that there is an interest in continuing to improve and enhance the Right Track program in the state.
 - Roxane also noted that the Department of Public Instruction has put together a 30 person advisory group to address the early childhood study that was contained and funded in SB 2229 during the last legislative session. The study is to be comprehensive in nature. A link to the activity around this study can be found at: http://www.dpi.state.nd.us/EarlyChildhoodEduc/study.shtm. Presently, there are 3 members of the NDICC that also serve on this work group and they are: Jennifer Barry, Allison Dybing-Driessen, and Nancy Skorheim.

TOPIC: NDICC LEADERSHIP ELECTIONS

Due to lack of quorum at the September, 2013 meetings, the election was held via a survey monkey. Fifteen of the 24 members voted constituting a simple majority. The results of the election were as follows:

- Jill Staudinger was elected the chair.
- Allison Dybing Driessen was elected the vice chair

TOPIC: STANDING NDICC AGENDA ITEMS

- Part C Budget Report Tina Bay provided this report and noted that we are currently spending FFY 2012 funds from the federal grant. Tina reported that according to the Part C budget report as of 9.30.13, \$188,359 has been spent on direct services. These are the direct Infant Development services that cannot be billed out through the Medicaid waiver, either because the child is not yet enrolled (first partial month), child can't be enrolled due to some extenuating circumstances, or because the family has chosen to not apply for Medicaid for the child. As reported to the NDICC in the past, this number has grown and the dollar amount expended in Direct Services has grown since ND started implementing the parent option to not apply for Medicaid. The report as of 8.30.13 which was presented at the September meeting was roughly \$95,000. It was noted by a Council member that it is extremely difficult to understand the application forms that are presented to the family and that all of the assistance that DD Program Managers could provide would be appreciated. A follow-up comment stated by a Council member is that providing advice on applying for Medicaid can be difficult because there is concern that something may not be accurate and this could affect the family NDICC Membership Update - Region IV parent is the only current opening. Roxane offered to contact a family member that she knows in Grand Forks.
- DD Slots Report Tina Bay provided this report and noted that the current ID/DD waiver expires 3/30/14 and is up for renewal. At the current time there are 170 slots left until the end of March. Tina noted that the state has 190 reserved slots of which 135 are for Early Intervention. Tina reminded the Council that slots are not recycled unless someone dies. This means that if someone comes in on April 1 for only 30 days, that slot is not available to anyone else for the remainder of the year. If we hit the reserved capacity, slots will have to be approved by the State Office. Autism waiver currently has eighteen slots filled. The Autism waiver was approved for five years. Presently, the state office is working on amendments to the Autism waiver in order to incorporate the additional slots and additional service changes that were passed this past legislative session. Tina noted that the renewal language for the ID/DD Traditional Waiver was sent out via a tribal notification which is required; however the state also opened up the language for general public comment and this closed Dec 1st. The state office will also be holding a public information meeting to discuss some comments on next Thurs, Dec 12, 10 to 12 via polycom.

- Committee Reports Roxane reported that there was email exchange with joint chairs of the NDICC and the IDEA Advisory Committee to talk about the September, 2014 meeting. No Executive Committee or Early Intervention Services Subcommittee meeting was held. There are 2 current issues for EI Services Subcommittee: Infant Development Payment System and Family Survey to be addressed prior to March, 2014 meeting.
- General Supervision Work Plan Roxane provided this report. The state office is currently pulling data for the FFY 2012 Annual Performance Report. The NDICC will be presented with the data at the January, 2014 meeting. Presently, the state office is sending query information to the regions in order to clarify the data. The state office made a decision on Indicator 7 which has to do with having an IFSP completed within the 45 day time line that we would have the field provide information on missing data from Therap so that we are able to account for it on the APR; however we will talk about the missing data information for the Valid and Reliable Data field on the Level of Determination. There are currently five programs in regional action plans and working on issues from the FFY '11 APRs; however all fo the findings from FFY '11 are now closed. Roxane noted that the state has developed strong procedures around collecting, analyzing and reporting state data. This has been followed by predictable patterns of issuing findings, tracking and closing findings. ND received extensive technical assistance from the Data Accountability Center through Sharon Walsh for over a year and half. ND continues to utilize national technical assistance and will be meeting with our representative from Mountain Plains Regional Resource Center next week. ND was in the "Nees Intervention" category after the FFY '11 APR and is hoping to move out of this category in FFY '12.
- Autism Task Force Updates: A statewide Autism Conference is scheduled for Oct 20, 21, and 22, 2014, at the Doublewood Inn in Bismarck. A conference planning group is working with Trisha. There will be public input sessions on the amendment proposed for the Autism Waiver in December via the state HSC polycom system. A link will be sent out to the membership. Roxane noted that the Sanford Children's Advocacy Center just put out information to assist parents and law enforcement to be prepared in situations where children are wandering away from home.

TOPIC: OLD BUSINESS

Discussion about Affordable Health Care Act (ACA) and Impact on ND EI Families — Roxane noted that there had been discussion about putting together a panel around ACA and that this will be planned for the March meeting. She noted that two issues have developed for families that appear to be linked to the ACA. The first has to do with how "habilitation services" is being defined in our state. Some families have seen a drop in their coverage for related therapies because "rehabilitation services" were cut. In addition, there is some concern that families who enter into insurance purchased on the exchanges will not be able to have their child (who may be waiver or buy-in eligible) be on both Medicaid and the private insurance. A Council member noted that this would be concerning if a child requires the services on the waiver. Recommendation was that we continue to bring information to the Council on ACA and its impact on young children and their family.

• Family Information on Insurance Coverage – Did not address

TOPIC: NEW BUSINESS

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- FFY '12 Annual Performance report What to Expect at the January, 2014 NDICC meeting Roxane has a power point to send to the members.
- Recommended Activities around release of AAP Report on Medical Home and Early
 Intervention The link for the report was sent to NDICC members ahead of the
 meeting. Roxane noted that the ND chapter of the American Academy of Pediatrics
 received a grant on collaboration between home visiting programs and pediatrics.
 Comments from Council Members:
 - This could be used at the regional level in presenting to clinics and doctors about Early Intervention.
 - This could be used legislatively to educate them about the benefits of Early Interention.
 - The referral form was user friendly and as a state we could highlight sections that we want to draw attention to
 - Suggestion to see if ICC membership could do a presentation at a statewide
 APP meeting and use the clinical report as a basis for the presentation.
 - Use report to support the coaching model to get physicians to mentor each other.
 - Roxane noted she had spoken to Dr. McDonough and his suggestion was to target the information to the younger physicians.
 - Continue to figure out ways to get information from the Council meetings out to the general public for use.

Decision: Roxane will call Dr. Connel (comes to CSHS on Tues mornings), who is the president of the ND chapter of the AAP to discuss a presentation. She will also send out a reminder to NDICC members who may want to work on this project.

- <u>El Services Subcommittee Membership/Leadership</u> Roxane requested input on membership for the Early Intervention Services Subcommittee. She noted she would like to see representation from some Council members and other stakeholders. There is currently a parent in the Dickinson area who has agreed to be on the subcommittee. Typically we've had a core group and then have brought in other stakeholders depending on the topic. Recommendation to assure that Experienced Parents participate in the discussion on Family Surveys.
- NDICC Operations Evaluation tabled until March.

TOPIC: CALENDAR FOR 2014

- The January 16 was changed to January 17 from 1pm to 5pm and January 23 from 1pm to 5pm as polycom was not available on January 16. A motion was made by Shawnda Ereth and seconded by Tina Bay. Motion carried.
- A motion was made by Carol Brakel and seconded by Nancy Skorheim that the NDICC will meet on Sept 10 and 11. Motion carried.
- March 6 is 1pm to 5pm via polycom
- June 5 is 8:30am to 5pm at the Comfort Inn

North Dakota Interagency Coordinating Council

December 5, 2013

• Dec 4 is 1pm to 5pm via polycom